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Disability statistics

Joint report of the Secretary-General and the Washington Group on Disability Statistics

Summary

The present report, which was prepared in accordance with Economic and Social Council decision 2017/228 and past practices, provides an overview of activities by key stakeholders in the area of disability statistics. The report contains a section prepared by the United Nations, which describes activities of the Statistics Division of the Department of Economic and Social Affairs of the Secretariat, the regional commissions and the World Health Organization (WHO) and a section prepared by the Washington Group on Disability Statistics describing its activities.

Points for discussion by the Commission are presented in paragraph 72.

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I. Introduction

1. The 2030 Agenda for Sustainable Development, contained in General Assembly resolution 70/1, pays significant attention to persons with disabilities in the context of development, particularly in line with the principles that no one will be left behind and to reach the furthest behind first. The 2030 Agenda recognizes persons with disabilities as one of the groups of vulnerable persons and calls for their empowerment. It also underscores that follow-up and review of the Agenda will require quality, accessible, timely and reliable disaggregated data to allow progress to be measured and to ensure that no one is left behind, as such data is key to decision-making. In this context, the 2030 Agenda commits to enhancing capacity-building support to developing countries, including for least developed countries and small island developing States, in order to increase significantly the availability of high-quality, timely and reliable data. Moreover, the Convention on the Rights of Persons with Disabilities (General Assembly resolution 61/106) calls on States parties to that Convention to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies related to the Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights. States parties are encouraged to disseminate the statistics and ensure their accessibility to persons with disabilities and others.

2. Availability of data on disability has improved significantly over the years as the number of countries collecting data on disability in all parts of the world has progressively increased, starting in the early 1980s. This can be attributed mainly to continued international attention addressing the rights of persons with disabilities with the objective of streamlining disability into national development agendas. Nevertheless, there are still wide variations in estimates of disability both among countries and within countries over time. These observed differences bring into focus the diversity in national experiences and expertise across countries as well related cultural contexts within which the identification and measurement of disability takes place.

3. Critical decisions need to be taken so that countries can achieve tangible and measurable inclusiveness of persons with disabilities into national development programmes as required by the 2030 Agenda and the Convention. For monitoring purposes, there is an urgent need for high-quality and relevant statistics on disability, the issues stated in paragraph 2 above notwithstanding. It is recognized that a long-term strategy is required in order to develop a holistic approach so as to achieve fundamental improvements in the collection, analysis, dissemination and utilization of statistics on disability. States recognize in the 2030 Agenda that there are different approaches, visions, models and tools available to each country, in accordance with its national circumstances and priorities, to achieve sustainable development. In this context, it is imperative to have a long-term and coordinated strategy across all international partners for strengthening national capacity to generate robust statistics on disability for national planning and monitoring.

4. The present report describes ongoing and planned activities on disability statistics carried out by various offices of the United Nations and by the Washington Group on Disability Statistics, a city group under the aegis of the Statistical Commission. Points for discussion are presented in paragraph 72.

II. Ongoing and planned activities by United Nations organizations

A. Statistics Division

5. At the international level, the Statistics Division is responsible for the development of international statistical methodological standards, the compilation and dissemination of official statistics and the provision of technical assistance for strengthening national statistical capacity. Since May 2015, the Division has received funding from the Department of Foreign Affairs and Trade of the Government of Australia for implementation of the disability statistics programme. Ongoing and planned activities on disability statistics by the Statistics Division are described below.

Regional meetings on disability measurement and statistics in support of the 2030 Agenda for Sustainable Development and the 2020 World Programme on Population and Housing Censuses

6. In 2016 and 2017, the Statistics Division, in collaboration with the regional commissions, organized six regional meetings whose objectives were to: (a) review and discuss national experiences regarding approaches taken to measure the population with disabilities during national censuses of the 2010 round, including challenges faced and lessons learned; (b) provide an opportunity to discuss strategies for compilation of data on disability for the monitoring of the Sustainable Development Goals; and (c) share national experiences among participating countries and facilitate intraregional cooperation aimed at enhancing national capacity in disability measurement and improving the quality of data for monitoring the Goals. The Division has so far organized the following meetings: South and South-East Asia in July 2016 for 19 countries; the Caribbean region in September 2016 for 14 countries; Africa in November 2016 for 14 English and French speaking countries; Arabic-speaking countries in March 2017 for 11 countries; the North and Central Asia region and Western Balkan States in June 2017 for 17 countries; and Latin American countries in June 2017 for 15 countries. Reports of and presentations made at the regional meetings are available on the disability statistics programme website at http://unstats.un.org/unsd/demographic/sconcerns/disability/disab4.htm.

7. Some observations from the regional meetings include: (a) differences among countries in the questions that are being asked to identify the population with disabilities during national censuses with regard to the terminology used, the implied definition of the population to be identified, the number of items in the question(s), the response categories, and the use of and wording of screening questions; (b) differences in the type of respondent and the population covered in the collection of data on disability (e.g. inclusion or exclusion of children); (c) wide variations among regions in sources for data on disability, with some regions having strong reliance on censuses to collect data on disability and other regions making extensive use of multiple sources (censuses, administrative records, surveys) to compile data on disability; (d) recognition in all regions that administrative sources of data on disability should be strengthened and exploited; (e) acknowledgement by countries that in the context of the 2030 Agenda, an unprecedented amount of statistics would need to be produced by national statistical systems, requiring a data revolution that explores alternative sources of data as well as coordination of the system; (f) a general lack of the requisite formal national coordination mechanisms for all the necessary stakeholders in countries; and (g) a general lack of experts on disability statistics in

countries. These observations highlight the need for comprehensive statistical capacity development programmes that would strengthen national capacity in the collection, analysis, dissemination and utilization of data on disability in the countries.

Development of methodological guidelines

8. The Statistics Division, in collaboration with relevant stakeholders, is updating the Principles and Guidelines for the Development of Disability Statistics,[1] which provide methodological guidelines to producers of disability statistics for improving the collection, compilation and dissemination and usage of data on disability. Compared with the current version, the revised guidelines highlight the importance of instituting a well-coordinated national policy to ensure effective demand for data, establishing a national statistical programme that responds to the policy data needs, measuring facilitators and barriers to functioning, and developing strategies to enhance the analysis, accessibility and utilization of data on disability in countries. The Division has constituted a group of experts for the revision of the Guidelines and organized a meeting in July 2017 to seek the views of the experts in identifying issues and areas where these guidelines should be revised or further enhanced.[2] The experts were chosen taking into account geographical representation in order to ensure international relevance of the revised guidelines.

Collection and compilation of national data and metadata on disability

9. The Statistics Division, in collaboration with regional commissions, is collecting, from national statistical offices, statistical data and supporting documents, such as questionnaires, from recent censuses, surveys and administrative sources. To date, the Division has collaborated with the Economic and Social Commission for Asia and the Pacific (ESCAP), the Economic Commission for Africa and the Economic Commission for Latin America and the Caribbean (ECLAC). The collected information will form the basis for analysis of national practices regarding disability measurement and for compilation and dissemination as data on the prevalence and characteristics of persons with disabilities.

Maintenance of website

10. The website of the disability statistics programme has been updated and is strategically located as part of one of the major work programmes[3] of the Statistics Division. The website is a resource centre for international exchange and sharing of technical knowledge and information in the area of disability statistics and measurement. The website also provides links to other relevant resources, including to the websites of the secretariat of the Convention on the Rights of Persons with Disabilities, WHO, the United Nations Children's Fund (UNICEF), the 2030 Agenda for Sustainable Development and the Washington Group on Disability Statistics.

Other activities

11. The Statistics Division is providing substantive inputs for and is also coordinating the contributions of other stakeholders to a chapter on data on disability and opportunities and challenges, which will be included in an upcoming flagship

[1] https://unstats.un.org/unsd/pubs/gesgrid.asp?id=269.

[2] https://unstats.un.org/unsd/demographic-social/meetings/2017/new-york--disability-egm/.

[3] http://unstats.un.org/unsd/demographic/default.htm.

report in 2018 on disability and development and realizing the Sustainable Development Goals by, for and with persons with disabilities. The chapter covers current efforts by countries to measure disability and identifies strategies to enhance national capacity to meet data demands for disability-inclusive development.

Planned activities

12. The Statistics Division plans to organize a second meeting in July 2018 for the group of experts to review a draft of the revised Guidelines and Principles for the Development of Disability Statistics. When finalized, the revised guidelines will be used in training workshops aimed at building national capacity to collect data on disability in accordance with international standards.

13. The collection of data from countries will be continued during 2018. The arrangement to collect the data in collaboration with the regional commissions is intended to minimize duplication of effort and avoid overburdening countries with multiple requests for the same data. In some instances, the Statistics Division will contact countries directly to obtain the data.

14. The Statistics Division plans to organize more regional meetings that bring together senior experts responsible for disability statistics from national statistical offices and senior officials from institutions that are responsible for national policy on disability, as well as participants from some organizations of persons with disabilities. The main objective of the meetings is to review the existence of national coordinated mechanisms for producing and utilizing disability data for policy purposes and identify gaps and strategies for strengthening national capacity.

15. The website will continue to be developed incrementally and currently has both recent and some dated information that will either be replaced or supplemented with new information as it becomes available.

B. Economic Commission for Latin America and the Caribbean

16. While all countries in Latin America and the Caribbean are collecting statistical information on the situation of persons with disabilities, the heterogeneity in the criteria used for measuring disability, including variations in the definition of disability and variations in the application of international guidelines, including the sets of questions recommended by the Washington Group, make it necessary to strengthen the capacity of national statistical offices and promote a greater harmonization of data-gathering processes. ECLAC is actively working to improve the quality and comparability of data, by serving as the technical secretariat for the Disability Measurement Working Group of the Statistical Conference of the Americas and by providing technical assistance on disability measurement, as requested, by ECLAC member States.

17. With the support of ECLAC, the Disability Measurement Working Group fulfilled its mandate for the 2014–2017 period with the preparation of a report that details disability measurement procedures in Latin America and the Caribbean[4] and the organization of two regional workshops, one focused on the application of the International Classification of Functioning, Disability and Health[5] and the other on

[4] https://www.cepal.org/deype/noticias/documentosdetrabajo/0/53340/LCL3860e.pdf

[5] https://www.cepal.org/deype/ceacepal/2017-CE16/DDR/CE16-GTMD-Informe-seminario1-09-2016.pdf

the application of the Washington Group sets of questions with a view to the next census round.

18. For the biennium 2018–2019, the Disability Measurement Working Group aims to: (a) improve the technical capacity of countries in the region to collect and disseminate International Classification of Functioning-based disability data in line with international recommendations such as those of the Washington Group, the Statistics Division, WHO, UNICEF and the International Labour Organization (ILO), among others; (b) develop a methodological/conceptual proposal related to the design and execution of statistical projects to generate information on disability in the countries of the region; (c) provide technical guidance to the countries of the region to strengthen the inclusion of disability in the next census round, based on international recommendations; and (d) build a support network among institutions, national and international agencies (including other working groups of the Statistical Conference of the Americas, such as the Census Working Group and the Working Group on Statistics on Children and Adolescents), experts and users and generators of statistical information on the population with disabilities.

19. The specific activities that will be carried out to achieve these objectives include: (a) the preparation of methodological proposals to support the application of international recommendations for the measurement of disability in censuses and other data-gathering instruments during the first half of 2018; (b) a meeting, towards the end of 2018 or in the first quarter of 2019, to exchange experiences on disability measurement, based on the census pilot tests carried out during 2017 and 2018; and (c) during the second half of 2018, the creation of a directory of officials of national statistical offices, disability offices and councils or ministries responsible for producing data on disability in the region, and a directory of international organizations that have developed or participate in methodologies for measuring disability. The updated directories will be available on the webpage of the Disability Measurement Working Group, along with other reference materials. These activities have potential for collaboration with the Statistics Division given its central role at the international level.

20. ECLAC will also provide technical assistance to member States in preparation for the 2020 census round. ECLAC is currently reviewing the disability-related questions in the census questionnaires of Guatemala and Argentina. Finally, in December 2017, ECLAC led a training workshop in Costa Rica at the request of the national disability council (CONAPDIS) on producing indicators to assess the human rights situation of persons with disabilities in the country.

21. ECLAC will contribute to the review of the Guidelines and Principles for the Development of Disability Statistics by providing examples of national experiences and good practices in the use administrative records from Latin America. In order to gather experiences from the countries of the region, a virtual seminar will be organized and the outcome report of the seminar will serve as the basis for the input.

C. Economic and Social Commission for Asia and the Pacific

22. The work of ESCAP on disability statistics falls within the realm of the implementation plan for the regional strategy to improve population and social statistics in Asia and the Pacific, which was endorsed by the ESCAP Committee on Statistics at its fifth session, in December 2016. The implementation plan sets out a framework that can be used to identify issues related to capacity-building on disaggregated data in the context of the Sustainable Development Goals. More

specifically, the framework identified three broad areas of work, namely: (a) establishing an enabling policy environment to create and sustain demand for statistics for inclusive development; (b) strengthening production and dissemination of data; and (c) enhancing accessibility and use of statistics to inform policy debates.

23. The Regional Steering Group on Population and Social Statistics at its first meeting, held in Bangkok from 28 August to 1 September 2017, finalized a workplan in line with the three broad areas of work. Through a systematic focus, beginning with the creation of an enabling policy environment and strengthening national indicator frameworks as a critical link between policy issues and data improvement, ESCAP plans to identify and disseminate specific strategies for promoting efficient national production and utilization of data on persons with disabilities, among other population groups. The basic tenet is to ensure that the data is responsive to national disability policy priorities. The process will thus require the engagement not only of national statistical offices and statistical units within line ministries, but also other relevant national agencies such as national disability policy agencies, civil society partners and organizations of persons with disabilities, leading to the development of more integrated and comprehensive disability data production systems.

24. The Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific, a policy framework for the region, not only enshrines the principle of disability-inclusive development, it provides the region and the world with the first set of regionally agreed disability-specific development goals and targets, accompanied by indicators to enable progress tracking. Goal 8 of the Incheon Strategy focuses on improving the quality of disability data. The recent high-level intergovernmental meeting on the midpoint review of the Asian and Pacific Decade of Persons with Disabilities, 2013–2022, held in Beijing from 27 November to 1 December 2017 and organized by ESCAP in cooperation with the China Disabled Persons' Federation, discussed the importance of generating baseline data as a starting point to track progress on disability-inclusive development. Persisting challenges for disability data production include the lack of a common understanding of concepts and operational definitions related to disability among relevant national stakeholders, the need to shift away from the medical to the biopsychosocial model in improving disability data and resource constraints for data collection. Participants emphasized the importance of political will and multi-stakeholder engagement as critical means to improve disability data. In addition to calling for increased harmonization between various questions and instruments that were available internationally for disability data collection, the meeting also called for exploring and harnessing non-traditional data sources and innovative approaches, such as geospatial information, to enhance disability data production.

25. The outcome document of the meeting, the Beijing declaration and action plan to accelerate the implementation of the Incheon Strategy, called upon Governments to map the status of disability statistics across ministries and develop and implement national action plans to improve the reliability and usability of disability data. It also called upon Governments to examine the concepts, purposes, targets and advantages of existing disability data collection tools and instruments through censuses and surveys, including the tools developed by the Washington Group on Disability Statistics for measuring disability, those developed by the Washington Group and UNICEF for measuring child disability and the WHO model disability survey. The declaration further calls on Governments to establish or improve national registers and civil registration and vital statistics systems as viable sources of data on disability. Sustainable resource allocation for building statistical capacity in disability data collection was highlighted as a critical means to improve data on disability.

26. ESCAP has been working closely with the Statistics Division to organize regional and subregional meetings in Asia and the Pacific. Meetings covering national statistical offices and national disability policy agencies in South-East Asia, South and South-West Asia and East and North-East Asia (in 2016) and North and Central Asia (in 2017) compiled national experiences and identified challenges faced and lessons learned in measuring disability from different sources of data, including the last round of the population and housing census, in addition to identifying the way forward towards the compilation of data on disability for monitoring the Sustainable Development Goals.

27. In line with the above ongoing and planned activities to improve disability data in the Asia-Pacific region, ESCAP will continue to collaborate with the Statistics Division in the revision of the Guidelines and Principles for the Development of Disability Statistics, with case studies and experiences gathered through the regional work serving as inputs for various components of the Guidelines and Principles, and in organizing a meeting/capacity-building workshop for countries in the Pacific subregion with objectives similar to the previous meetings conducted in the period 2016/17.

D. Economic and Social Commission for Western Asia

28. The Economic and Social Commission for Western Asia (ESCWA) initiated its disability programme in 2016 and implemented three interlinked activities in the region between 2016 and 2017. The first activity, initiated in June 2016, was to compile national data on disability through a questionnaire on disability statistics and make an assessment of practices used to implement various collection tools. The compiled information provided a wealth of data on persons with disabilities. In addition, it revealed a need for capacity-building efforts to address various national implementation practices. The second activity was to organize an expert group meeting on disability measurement and statistics in support of the 2030 Agenda for Sustainable Development and the 2020 World Programme on Population and Housing Censuses in collaboration with the Statistics Division, which was held in Muscat in March 2017. The third activity was to organize a regional workshop on improving disability statistics in the Arab countries, held in Casablanca, Morocco, in April 2017, in collaboration with the Washington Group. The workshop focused on best practices for implementing the Washington Group short set of questions and reviewed challenges encountered in collecting disability statistics and improvements to practices to implement the short set of questions. A technical publication (a regional guidebook to improve disability data collection and analysis in the Arab countries) is the outcome of these three activities.

29. As an outcome of the activities described above, ESCWA, in collaboration with national statistical offices, published an online bulletin on Arab disability statistics in numbers for 2017 based on national data, harmonized to the extent possible to allow for regional analysis, based on different sources. The bulletin presents figures concerning the situation of persons with disabilities in comparison with those with no disabilities. The bulletin will be updated periodically as countries collect more disability statistics. The scope of areas covered will also be expanded to allow further in-depth analysis in the future.

30. In collaboration with the Washington Group, ESCWA developed the first guidebook at the regional level to improve disability data collection and analysis in the Arab countries implementing the Washington Group questions. The guidebook

aims to improve the collection, analysis and availability of data on persons with disabilities by providing guidance on how to standardize implementation of the Washington Group questions and related indicators. The guidebook has six chapters and includes topics on the following: (a) the role of disability statistics in policy analysis; (b) the concept of disability and its implication for designing disability data collection efforts; (c) the Washington Group disability data collection tools; (d) implementing the Washington Group questions and best practices for data collection; (e) measuring prevalence and analysing disability data; and (f) summarizing Arab-region experience in data collection and recommendations to improve data collection methods and to capture the majority of people with disabilities.

E. World Health Organization

31. WHO has a long-lasting tradition in the conceptualization and measurement of disability and achieved an important milestone with the endorsement of the International Classification of Functioning, Disability and Health by all WHO member States at the fifty-fourth World Health Assembly, in 2001 (resolution WHA54.21). WHO has been engaged in the measurement of functioning and disability in a number of data collection efforts, including: (a) the multi-country survey study; (b) the World Health Survey; (c) the study on global ageing and adult health; and (d) the WHO disability assessment schedule. WHO is presently supporting member States to collect disability and functioning data at the population level using the model disability survey, which is a general population household survey.

Model disability survey

32. The model disability survey was developed by WHO and the World Bank in 2012, in collaboration with a range of stakeholders from other international organizations, leading researchers and persons with disabilities and their collective organizations, to support WHO member States in establishing and strengthening their monitoring and evaluation systems for disability, as requested by the World Health Assembly in 2013 (resolution WHA66.9) and the WHO global disability action plan 2014–2021, adopted by 194 member States at the sixty-seventh World Health Assembly, in 2014. The model disability survey is designed to identify and address barriers and unmet needs, to formulate policies and evidence-based national disability strategies and to help assess progress made by States parties' in respect of their obligations regarding the Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development.

33. The model disability survey is fully grounded in the International Classification of Functioning, Disability and Health and conceptualizes disability as the outcome of the interaction between health conditions and the physical, human-built, attitudinal and sociopolitical environment of a person. Disability is therefore not only an individual attribute based on the presence of health conditions and impairments, but a multidimensional experience generally characterized by limitations in functioning in multiple life areas, such as problems with mobility, self-care, communication or work depending on how impairments and health conditions play out in a person's real-life environment.

34. The model disability survey also conceives disability, in line with the International Classification of Functioning, as a continuum, ranging from no disability, to low and to very high levels of disability. Disability is thus a matter of

degree: any person with health conditions or age-related decline in health will experience disability to some extent at some point in life.

35. To capture and describe disability from a comprehensive perspective, the model disability survey has three core modules: environmental factors (targeting barriers and unmet needs), functioning and disability, and health conditions and capacity. Five additional modules provide information about relevant indicators: sociodemographic characteristics, work history and benefits, health care utilization, well-being and empowerment.

36. The development of the model disability survey included a one-year preparatory phase to inform the selection of domains and questions: 179 health and disability surveys implemented worldwide since 2001 were assembled and mapped to the International Classification of Functioning and a selection of these underwent data analyses. The preliminary draft of the model disability survey was then reviewed at an expert meeting, held in December 2012 and attended by 28 international stakeholders from 20 countries. The alpha version of the survey was subsequently proposed and underwent three rounds of cognitive testing (between 2013 and 2015) in different countries and languages. Two major pilot studies were carried out, in Cambodia in 2014 and in Malawi in 2015. Pilots were used to test the structural validity of the disability scales and the overall performance of the tool.

37. Two versions of the model disability survey are currently available: a standalone version that is ideal for a dedicated survey on disability and a brief version that could be used as a module to be integrated into existing household surveys.

38. The brief version of the model disability survey module was developed in 2016, following extensive analysis of data from pilot and national datasets, consultations with international experts and engagement of people with disability, to meet calls from member States for a version of the survey that would be appropriate for integration into existing and regularly implemented household surveys, such as labour force or living standards and expenditure surveys. The brief version of the survey allows a continuous monitoring of the distribution of disability in populations and makes a disaggregation of indicators by level of disability possible, as required for the Sustainable Development Goals.

39. In 2015, the model disability survey was implemented nationwide as a dedicated disability survey in Chile and Sri Lanka. In 2017, further nationwide implementations in the Philippines and Qatar followed. The survey was also implemented regionally, in Cameroon in 2016 (Adamawa) and in Pakistan in 2017 (Baluchistan) and piloted in Dubai, United Arabic Emirates, in preparation for its full implementation in 2018. The brief version of the survey will be implemented in 2018 in India, the Lao People's Democratic Republic and Tajikistan through an existing data collection platform.

40. WHO provides member States with technical support throughout the implementation process, with a strong focus on sustainable capacity-building strategies for national or regional statistical offices. For instance, the approach used by WHO to analyse disability data and create valid disability scales with cardinal properties has been already applied by the National Statistical Office of Chile to other surveys. Workshops for interviewers and on data analysis have been conducted so far in Cambodia, Chile, Oman, Panama, Pakistan, the Philippines, Qatar, Sri Lanka and the United Arab Emirates. Materials for the model disability survey, including the questionnaires and an interviewer manual, are available either at http://www.who.int/disabilities/data/mds/en/ or on request.

41. The brief and long versions of the model disability survey enable disaggregation of all other outcomes of interest, such as employment, income and education, by disability status. It further enables this disaggregation by severity of disability. When the brief version of the survey is included in other surveys such as labour force, living standards or multi-topic surveys, it enables direct comparisons of these outcomes between persons with varying levels of disabilities and those without. The survey also enables countries to go beyond disaggregation, in making progress towards the realization of the Sustainable Development Goals and the implementation of the Convention on the Rights of Persons with Disabilities, and identify the right policy and programmatic actions to reduce inequalities and monitor the impact of these policies over time.

Planned activities

42. Workshops with statistical offices, health authorities and WHO regional and country offices are planned for 2018 in the six WHO regions of the world. These workshops aim to disseminate the model disability survey and encourage the use of the standalone survey as a dedicated disability survey and of the brief version of the survey as a disability module, especially in light of the need of disaggregate Sustainable Development Goal indicators by disability.

43. WHO will support launching events in 2018 in Sri Lanka, the Philippines, Qatar and the United Arab Emirates, to officially present findings of the model disability survey to country authorities, advocacy and support organizations, academics, researchers and the media. These events are structured to facilitate the uptake of results from the survey in the development of evidence-based national disability strategies and policies.

44. WHO regularly uses and recommends the Guidelines and Principles for the Development of Disability Statistics to countries and is committed to contributing to their revision by the Statistics Division in 2018.

III. Washington Group on Disability Statistics

45. The Washington Group on Disability Statistics was constituted as a city group under the Statistical Commission in 2001 and held its first meeting in 2002. The Group was established to address the urgent need for improved and internationally comparable disability statistics. A major objective of the Group is to provide basic necessary information on disability that is comparable throughout the world. Currently, the Group has over 130 country members and 10 affiliate members. A total of 17 annual meetings have been held using a regional rotation system to facilitate attendance by all member countries. The 2016 meeting was held in Pretoria, hosted by Statistics South Africa, and the 2017 meeting was held in Sydney, Australia, hosted jointly by the Australian Bureau of Statistics and the Department of Foreign Affairs and Trade of the Government of Australia. The following section of the report will briefly review accomplishments of the Washington Group, but will focus on its work since it last reported to the Commission, in 2016.

46. To date, the Washington Group has developed a short set and an extended set of questions and, in collaboration with UNICEF, has developed a module on child functioning. All question sets were designed to be added to censuses or surveys. Work is continuing on the development of a module on inclusive education in collaboration with UNICEF and on disability and employment in collaboration with ILO.

Information on these tools is provided below. Most recently, the Group has been engaged in building disability data collection and analysis capacity at the country and regional levels. With funding from the Government of Australia, the Group's website has been redesigned to optimize accessibility and now contains a series of updated documents, a section on frequently asked questions and a growing number of blogs to assist data collectors and users as they adopt the question sets and analyse the resulting data. In addition, also with funding support from Australia, the Group has initiated regional and other workshops focused on the implementation of its data collection tools. Detailed information on the Washington Group and the rationale, development, testing and use of all its tools can be found at www.washingtongroup-disability.com.

Washington Group short set of questions

47. The Washington Group short set of questions is a set of six questions designed to identify (in a census or survey format) people with a disability, namely those at greater risk than the general population for participation restrictions due to the presence of difficulties in six core functional domains, if appropriate accommodations are not made (see www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/). Responses to each question are captured using four graded answer categories: no difficulty, some difficulty, a lot of difficulty, or cannot do. The six questions and four answer categories allow for the calculation of estimates for the level of functioning within each domain or among different combinations of domains. The tool should be used in conjunction with other data collection activities, that is by including the Washington Group short set of questions within a larger survey or registration form to enable disaggregation of outcome measures (employment status, educational attainment, etc.) by disability status.

48. The questions can also be combined to create a set of disability status indicators that describe different levels of functional ability based on the choice of graded thresholds. The short set of questions is especially well suited for disaggregating the Sustainable Development Goals. It creates an intuitively well understood, internationally comparable distinction between people with and without disabilities, namely people who have a lot of difficulty or who cannot do at least one of six core functional domains. Simply by adding the short set of questions to an existing survey allows for the disaggregation of all indicators generated by that survey.

49. Since its adoption in 2006, the Washington Group short set of questions has been:

- Used in censuses or surveys in over 80 countries
- Promoted by international aid programmes (Department for International Development of the United Kingdom of Great Britain and Northern Ireland and Department of Foreign Affairs and Trade of Australia), as the means to collect disability data in all programmes and projects
- Introduced as a means for collecting disability data in the Principles and Recommendations for Population and Housing Censuses (rev. 3) and the Economic Commission for Europe (ECE) Conference of European Statisticians recommendations for the 2020 censuses of population and housing
- Included in the demographic and health surveys of the United States Agency for International Development and the UNICEF multiple indicator cluster surveys
- Included in 70 surveys sponsored by the World Bank

- Adopted by ESCAP as a way of identifying people with disabilities for constructing their Incheon Strategy to "Make the Right Real" indicators
- Adopted by Development Initiatives in its P20 effort on monitoring outcomes for the world's poorest 20 per cent.

50. The Washington Group short set of questions has been supported or recommended for use in disaggregation by disability status for the Sustainable Development Goals, including in:

- Joint statements by United Nations organizations including: UNICEF, ILO, the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women); international disability consortiums (International Disability Alliance and International Disability and Development Consortium); the Department of Foreign Affairs and Trade of Australia; and the Special Rapporteur on the rights of persons with disabilities to the fourth (Geneva, November 2016) and fifth (Ottawa, March 2017) meetings of the Inter-Agency and Expert Group on Sustainable Development Goal Indicators
- Global Action on Disability Network meeting communiqué (2 and 3 March 2017, Berlin)
- Statistical Commission, in its report on the forty-eighth session (decision 48/109, on social statistics, para. (g))
- 25 Member States in a statement at the tenth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities.

51. The Washington Group set of short questions has been used by:

- United Nations organizations: OHCHR, UNICEF, ILO, the United Nations Population Fund, the United Nations Educational, Scientific and Cultural Organization, the Office of the United Nations High Commissioner for Refugees, the United Nations Development Fund, UN-Women and the Special Rapporteur on the rights of persons with disabilities
- International NGOs: Handicap International, Sightsavers, CBM
- Academia.

Washington Group extended set of questions

52. Because the Washington Group short set of questions was initially designed for inclusion in censuses, it was necessarily brief and therefore identifies most, but not all, people with disabilities (in particular it was not designed to directly identify persons with psychosocial disabilities).

53. The extended set of questions includes domains that could not be included in the short set, obtains more information on some domains than are provided by the short set and obtains information on the use of mobility assistive devises in order to assess functioning.

54. In addition to the six domains of the short set of questions, the extended set also includes the following functional domains: affect (anxiety and depression), pain, fatigue and upper body functioning. As with the short set of questions, the extended set of questions have scaled response categories so that the level of functioning in each domain can be described. The domains can also be combined to create disability status indicators capturing different levels of difficulty in functioning.

Washington Group/International Labour Organization module on disability and employment

55. Promoting equal opportunity and treatment in employment is a central element of the ILO decent work agenda. The ILO Declaration on Social Justice for a Fair Globalization of 2008 indicates that various forms of equality and non-discrimination must be considered to be cross-cutting issues in the strategic objectives of decent work.

56. While necessary to address the strong policy interest in establishing and monitoring the effectiveness and impact of national legislation, programmes or policies to promote equal employment opportunity and treatment in employment for people with disabilities, comprehensive data on the employment situation of this population group is rarely available at the required level of detail and periodicity. Significant activities are needed to increase national capacity to venture into new data collection initiatives, as well as to increase the frequency of data collection. The Washington Group and ILO therefore collaborated to produce a new module on disability and employment for inclusion in labour force surveys. This module was designed to be as compact as possible while still being able to produce a useful set of indicators on disability and employment.

57. The module is currently undergoing cognitive testing and covers the following:

- Disability identification (the Washington Group short set of questions plus two additional questions on upper body mobility that focus on lifting and using one's hands and fingers), date of onset and barriers that limit work behaviour
- Accommodation
- Attitudes
- Social protection (receipt of cash or in-kind benefits related to disability).

Washington Group/United Nations Children's Fund child functioning module

58. As the main global advocate for children, UNICEF has played a leading role in providing the world with current, high-quality information on the well-being of children, with a particular focus on the most vulnerable. As a first step in addressing the need for comparable data on children with disabilities, UNICEF supported the collection of data on this topic through the multiple indicator cluster survey starting in 2000 until the mid-2000s.

59. The Washington Group determined that a special set of questions devoted to measuring child functioning was needed to address the aspects of child development not addressed in previous methods. To attend to the unique situation of children, the Washington Group, in collaboration with UNICEF, embarked upon the development of a separate module that would specifically address child functioning.

60. The questions of the child functioning module follow the same principles as the Washington Group short and extended modules: to determine "disability" through a series of questions on difficulty of functioning that would place a child at risk of participation restrictions in a non-accommodating environment. The module is composed of two sub-modules: one for children 2–4 years of age and another for children 5–17 years of age. Domains of functioning include: seeing*, hearing*, walking*, communicating*, learning* and remembering, self-care (feeding and

dressing), upper body functioning*, behaviour*, emotions (anxiety and depression), coping with change, focusing attention, playing* and relationships.[6]

61. Where appropriate, domains in the child functioning module mirror those included in the short and extended sets of questions, but the questions are formulated differently to be suitable for use on children. The child's mother or, if the mother is not alive or she is not living with the child, the primary caregiver is the recommended respondent for this module.

62. The module on child functioning was launched in October 2016 and is currently available in Arabic, Chinese, English, French, Portuguese, Russian, Spanish and Vietnamese. The module on child functioning and the Washington Group short set of questions (for the population aged 18 and above) have been incorporated into UNICEF-supported multiple indicator cluster surveys (see also below). UNICEF has conducted regional capacity-building workshops to support disability statistics for children.

63. The child functioning module has been supported or recommended for use in disaggregation by disability status for the Sustainable Development Goals, including in:

- Joint statements by United Nations organizations including: UNICEF, ILO, OHCHR and UN-Women; international disability consortiums (International Disability Alliance and International Disability and Development Consortium); the Department of Foreign Affairs and Trade of Australia; and the Special Rapporteur on the rights of persons with disabilities to the fourth (Geneva, November 2016) and fifth (Ottawa, March 2017) meetings of the Inter-Agency and Expert Group on Sustainable Development Goal Indicators
- Global Action on Disability Network meeting communiqué (2 and 3 March 2017, Berlin)

United Nations Children's Fund/Washington Group module on inclusive education

64. To support the promotion of the right to education for children with disabilities through cross-nationally comparable data, UNICEF and the Washington Group are working on the development of a survey module on inclusive education to assess the school environment and participation. The purpose of this set of questions is to provide information that can inform policy, provide a statistical summary of environmental influences on participation in school and identify key areas with bottlenecks that can be followed up on. The questions focus on education through a formal mechanism (as opposed to home school or tutoring) and are designed to capture the interaction between the participant and the environment by obtaining parental responses to questions across three participatory domains.

65. The first set of questions is intended for the general adult population, with the purpose of capturing attitudes towards education for all children, and specifically for children with disabilities. The second section is meant to be administered to caregivers of children who are attending school. It includes questions that evaluate the accessibility of the physical space, the curriculum and other aspects of the school environment such as teachers' attendance, availability of toilet facilities and access to social activities. The final component focuses on out-of-school children and attempts

[6] Domains marked with an asterisk are relevant for children 2–4 years of age, all domains, with the exception of playing and upper body functioning, are relevant for those 5–17 years of age.

to gain a deeper understanding of the barriers to school participation, including safety, transportation, accessibility of the curriculum and affordability.

66. Since 2013, the module has undergone several rounds of cognitive testing and revision and is expected to be finalized in 2018.

Capacity-building

67. To date, implementation workshops have been held in Nadi, Fiji (Pacific Island region), Casablanca, Morocco (Western Asia), Rome (non-regional), Port of Spain (Caribbean region) and Mexico City (Latin America). A total of 54 countries have attended and participated in these workshops. Additional workshops are planned for South-East and Central Asia and Africa in 2018 with funding from the Department of Foreign Affairs and Trade of Australia. The Washington Group and UNICEF jointly sponsored workshops focusing on child disability in Tunisia, Geneva (for Europe and Central Asia), New York (for Latin America and the Caribbean), New York (for East Asia and the Pacific, South Asia, the Middle East and North Africa and Eastern and Southern Africa) and in Dakar (for West and Central Africa, the Middle East and North Africa and Eastern and Southern Africa). Two workshops were held specifically for disabled peoples' organizations. The Washington Group also continues to provide assistance and advice through webinars and phone and email as required and requested.

68. The need for a regional focus on disability statistics has become evident at the regional workshops held so far. While the best way to organize regional interests had not been developed, the Washington Group has been in discussion with countries and regional groups as to how best to address the ongoing need for capacity-building regarding disability statistics. The guidebook developed as part of the ESCWA workshop is one way to develop a regional focus. Other regions have expressed an interest in developing their own guidebooks and in having greater communication and collaboration within their regions. In the coming year, the Group will consider ways to develop stronger regional capacity.

Planned activities for 2018

69. Over the next two years, the Washington Group plans to continue activities related to capacity-building and to the development of new modules. The following activities will be undertaken by the four existing working groups: analysis and dissemination, child functioning, psychosocial functioning, and administrative data. Activities include:

- Continuing to develop guidance for the analysis and presentation of data collected using Washington Group data collection tools with a focus on more general analytic topics
- Finalizing and disseminating interviewer guidelines and manuals for implementing the child functioning module
- Continuing the development of the module on inclusive education
  - Continued analysis of cognitive test data and proposing revisions based on the test results
  - Further cognitive and field testing
  - Finalizing the module
  - Developing implementation guideline documents

- Continuing the development of the disability module for use in labour force surveys
- Continuing to work on the measurement of psychosocial functioning and develop new tools if needed
- Addressing the feasibility of collecting information on disability through administrative data systems
- Continuing regional workshops to facilitate the incorporation of the Washington Group short set of questions into censuses and surveys for use in monitoring the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals
- Collaborating with partners on projects of mutual interest.

70. The Washington Group disseminates its work products globally through the Internet (http://www.washingtongroup-disability.com) and scientific publications.

IV. Conclusions

71. Based on the reports of the various stakeholders on their ongoing and planned activities, some at the regional and others at the international level, it is important that there is adequate coordination and collaboration so as to better serve the priorities of the different regions and countries therein. Furthermore, these activities should strongly take into account the short-term and immediate needs of countries to embark on implementation of the 2030 Agenda for Sustainable Development, while also working on a medium- and long-term strategy to strengthen statistical capacity in the countries to be able to collect fit-for-purpose statistics on disability and utilize them for their national policy needs.

V. Points for discussion

72. **The Commission may wish to:**

(a) Express its views on the achievements and approve the planned activities of the United Nations organizations, including the Statistics Division, the regional commissions and WHO, as described in the present report;

(b) Endorse the creation of a group of experts for the revision of the Guidelines and Principles for the Development of Disability Statistics;

(c) Express its views on the achievements and approve the planned activities of the Washington Group, including the regional capacity-building activities, as described in the present report;

(d) Provide guidance on how to address disaggregation of data by disability status, especially in the context of the Sustainable Development Goals;

(e) Provide guidance on the most effective coordination mechanism for the work on disability statistics at the international level, for the short and long terms.